

Infant deaths in north Kirklees

January 2008



Infant deaths in north Kirklees – executive summary

During development of the North Kirklees Annual Health Report for 2005, the rates for infant deaths locally raised some immediate concerns.^a This resulted in the topic becoming a major priority for investigation by the Primary Care Trust and the Local Public Service Boards for Adults & Healthy Communities and for Children & Young People, as well as Mid Yorkshire Hospitals NHS Trust. This investigation only covers north Kirklees.

Method of investigation

Through close collaboration between the Primary Care Trust and Mid Yorkshire Hospitals NHS Trust, a detailed analysis of paper records of all the 106 infant deaths which occurred in 2002 to 2005 inclusive was carried out. Dialogue about the issues emerging from the analysis has also occurred with the lead clinicians for maternity, obstetrics and paediatrics.

Outcomes of the investigation

It should be recognised that infant deaths will still occur within the population, but locally the rates vary widely across all Kirklees localities with two localities being double the national rate and four localities having an upward trend, three of which are in north Kirklees.

Key infant features and factors

- The rates for both non South Asian and Pakistani populations in north Kirklees were higher than nationally.
- Half were of South Asian origin, mainly Pakistani, compared to 1 in 3 births being of South Asian origin.
- Over half were born prematurely i.e. before 37 weeks of gestation.
- Over half were also of low birth weight, which is linked to prematurity.
- Twice as many white babies, compared to Pakistani, were born before 31 weeks gestation. So, white babies tended to have prematurity as their cause of death whereas Pakistani had congenital abnormality, as they were more likely to be born near term.
- The cause of death is also related to the age of birth, as prematurity is a cause of death. This and congenital abnormality were responsible for over 2 in 3 of the deaths. Of those dying of congenital abnormality, only 1 in 4 were premature.
- Multiple births was far higher locally than nationally and mainly of white origin.

Key maternal features and factors

- Very few were at the extremes of age of motherhood i.e. under 18 or over 40 years.
- Sibling history of congenital abnormality existed for 1 in 6 of the babies, mainly in Pakistani families.
- 1 in 4 of all women booked later than 16 weeks, thus delaying the possibility of early identification of relevant factors to manage them.
- Screening for infection was high but for certain genetic screening was extremely low for South Asian mothers.
- Smoking was significant but alcohol and drug use was not.

From this there are clear local action points to reduce the current increasing local rate.



^a Infant deaths are babies born alive but dying in their first year.

Key action points

1. Supporting Healthy Personal Behaviours of Mothers during and after birth

The personal behaviours of mothers profoundly affect the health of their unborn child and the health of their existing children into their own adulthood. Key behaviours before, during and after pregnancy are:

- Not smoking before, during and after pregnancy and involving the whole family.
- Having good balanced nutrition also before, during and after pregnancy. Supplements should be considered of folic acid, iron and vitamin D when pregnant, at least. Ideally, all South Asian children and women should have such supplements particularly when pregnant or breastfeeding.
- stopping alcohol consumption and/or drug taking.

Key information and support is offered to all parents after birth, e.g. on breastfeeding, diet and reducing accidents.

Above all, smoking by the family significantly affects the health of the children so this remains a key priority for all services to support smoking families.

2. More awareness of genetic conditions which may cause infant death

Locally we need to understand better the impact genetics can have on future generations particularly in managing increased risk, including the role of consanguinity.

It is therefore recommended that the local NHS and Council contribute to the establishment of the proposed regional congenital anomalies register as a priority.

3. Good antenatal care is accessible and accessed

The importance of accessing antenatal care as soon as possible needs to be known within all communities. This enables the management of diabetes, particularly gestational, assessment of any genetic inheritance issues and multiple pregnancies as these carry higher risks of suffering infant death.

Locally, services need to ensure that they can also respond and support women whose first language may not be English. This will include provision of materials and information in an accessible way e.g. via link workers, and material devised in such a way that people who are not familiar with English and/or have a poor educational attainment are not disadvantaged. This also includes providing the opportunity locally to be able to learn English as a priority.

Work locally should also focus on ensuring all women are aware of and fully understand the screening programmes available and are able to make an informed decision about uptake.

4. Systems, processes and data

A range of analyses have not been possible to carry out because of the quality and availability of data. Data items to be collected need to be clearly defined, incorporated in recording forms and computer systems and support given to staff, if necessary, to ensure full capture occurs in a timely and accurate way.

Locally the recommendations of the 'Working Together to Safeguard Children' guide must be adopted, particularly the recommendations relating to child death review processes. This should link into the existing process for reviewing all infant deaths in Mid Yorkshire Hospitals NHS Trust and ensure that lessons are learnt and systems and processes improved in future.

5. Support for further research

Particular factors are known to contribute to infant death. In a number of areas further research is required to assess the impact, both locally and at a national level, particularly about factors which can lead to low birth weight and/or pre-term delivery. Any valid research proposals to inform these areas should be seriously considered for support by the Local Public Service Boards.

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1. Introduction

During development of the North Kirklees Annual Health Report for 2005¹, the Director of Public Health raised concern about increasing infant death rates. This resulted in the topic becoming a major priority for investigation by the Local Public Service Boards for Adults and for Children and Young People. This is a report of that investigation whose purpose was to try and identify the factors that affect infant death and to understand better what was happening locally, in order to see if the situation could be improved.

This report describes some of the factors that can contribute to infant deaths. It also describes the findings of an analysis of all such deaths in north Kirklees between 2002 and 2005 inclusive, in relation to these factors. Finally some recommendations for future actions are made to reduce such tragedies.

2. Definitions

Infant death is the term used to describe any deaths arising in children who are born alive but who die before their first birthday. Infant death has been used internationally as a key indicator of health status of a population, and has been used as a measure of inequality. The infant death rate is defined as the number of children **born alive** but dying within 364 days, per 1000 live births. One of the two national targets in 'Tackling Health Inequalities'² is to reduce by 10% the gap in infant death between manual groups and the rest of the population by 2010. Both the National Service Framework for Children³ and 'Every Child Matters'⁴ focus on the importance of reducing infant death.

Still Birth is the term applied to babies born after 24 or more weeks of gestation but who showed no signs of life at birth. The still birth rate is defined as the number of still births per 1000 **live and still** births.

Neonatal death rate is defined as the number of babies born alive but dying within 28 days per 1000 live births. These deaths are included in infant death. Neonatal refers to the same period after birth, i.e. 28 days.

Babies described as **not viable** are those born at 24 weeks gestation or less. Some babies do survive from this early gestational age, but many are not sufficiently developed to survive, hence the term applied.

Intra uterine growth restriction (IUGR) occurs when the baby is born full term but has inadequate foetal growth i.e. it has not developed to the size that would have been expected at full term.

Low birth weight babies are defined as those born weighing less than 2500 grams.

Gestational age is the number of weeks into the pregnancy that the baby was born.

Pre-term babies are those born under 37 weeks of pregnancy. Babies born after 37 weeks pregnancy are referred to as **mature**. **Prematurity** or babies born **prematurely** refers specifically to those babies born between 32 weeks and 36 weeks and 6 days.

Trimester: Pregnancy usually lasts 40 weeks, and this is divided up into thirds or trimesters i.e. of about 13 weeks each.

Morbidity is the collective term for ill health, especially disease.

Health inequalities are defined as differences in health between people which are unnecessary and avoidable, but also unfair and unjust.¹ These differences are influenced by a wide range of factors, including:

- **Individual characteristics** of age, gender, ethnicity and genetic make-up
- **Personal behaviours** – including smoking, diet and physical activity
- **The physical, social and economic environment** in which people live and work – including income, education, employment, housing, transport, food, crime, pollution and social support
- **Access to services** – poorer provision, uptake and quality of essential services in communities at greatest need of services and the over use of some non-essential services by more privileged groups.



3. What is the problem?

Figs 1-3 and 5 present the local rates compared to national over time, for stillbirth, infant and neonatal deaths. The data is displayed as 5 year averages, to allow for variations due to small numbers.

There were 37 deaths across Kirklees in 2005, of which 24 were in the north localities.

Infant death rates nationally have been decreasing since 1976, when the rate was 13.8 per 1000 live births, to 2005 when the rate had reduced to 5.2 per 1000 live births. This decrease has reflected, in particular, a decline in neonatal death.

From figure 1 across Kirklees there are wide inequalities between localities. Of concern is the trend upwards in four localities, most notably Batley, Dewsbury, Huddersfield North and Spen. Dewsbury itself was especially high, see Fig 5.

Figure 1 – Infant death rate per 1000 live births by locality, Kirklees, England & Wales 1994-2005



Source: Office of National Statistics

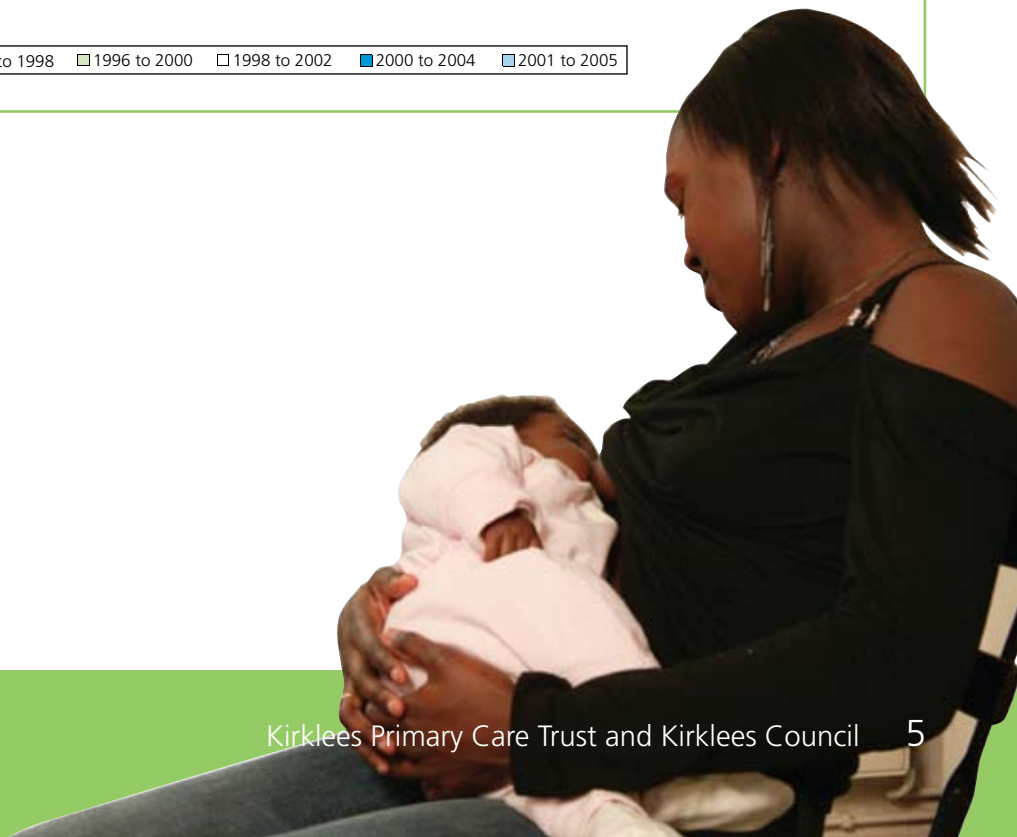
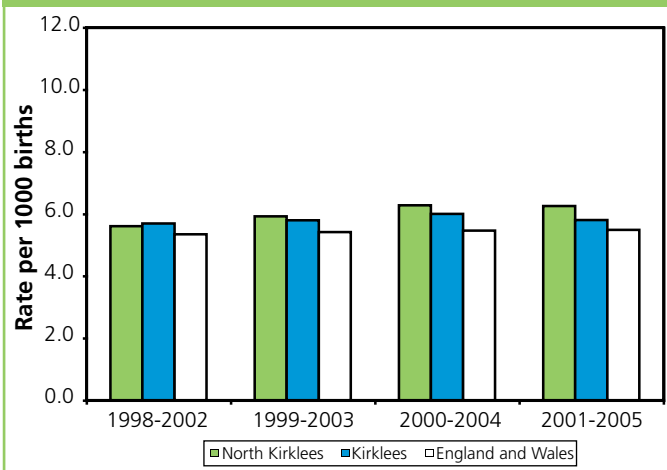
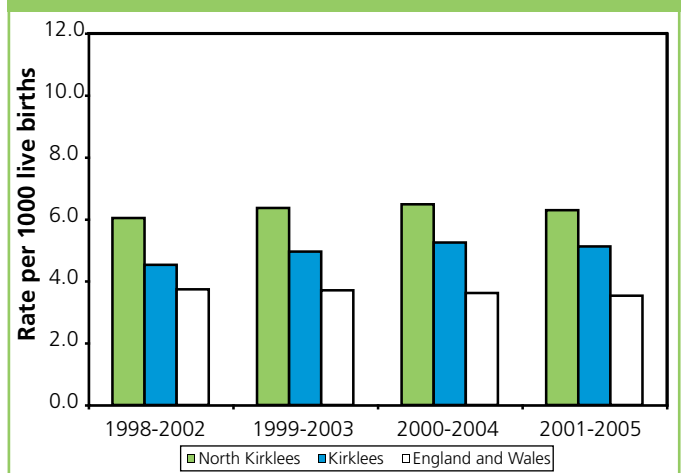


Figure 2 - Still birth rate north Kirklees, Kirklees, England and Wales 1998-2005



Source: Office of National Statistics

Figure 3 – Neo-natal death rate north Kirklees, Kirklees, England and Wales 1998-2005



Source: Office of National Statistics

4. Features and factors affecting infant death

There are a number of factors known to contribute towards infant death and features that are linked to them, which are described below. In most cases complex multiple factors are involved, rather than one single factor, some closely interrelated. No single intervention is likely to be particularly effective in contributing to a reduction in infant death.

In 2003, nationally 71% of all infant deaths related to events occurring in pregnancy, such as congenital abnormalities, infections and immaturity related conditions and 85% of all neonatal deaths⁵. Pregnancy therefore needs to be the focus for actions to reduce infant death.

Features affecting infant death

4.1 Age of mother

Nationally, between 1996 and 2000, mothers aged less than 18 years suffered the highest rate of infant death (10.1), compared to older mothers. However, infant deaths to mothers aged under 18 years accounted for only 4.4% of infant deaths nationally in 2000⁶. Their babies were more likely to have a lower birth weight.

Mothers aged over 40 had a higher infant death rate (6.6) than mothers aged between 20 and 40 but it was still lower than for mothers in their teens and accounted for only 3.2% of deaths nationally in 2000⁶.

4.2 Gender of the baby

Overall, slightly more boys are born than girls^{7,8}. Neonatal and infant death is higher in boys than girls. Stillbirth rates are generally similar between the sexes.

4.3 Ethnicity

Babies born in the UK of women born in Pakistan had higher infant death rates and a higher incidence of low birth weight when compared to other ethnic groups⁵. For example, in 2003 the infant death rate for women born in Pakistan was 10.5 per 1000 live births compared to 5.2 in the UK as a whole and 6.6 in mothers born in India⁹. Some of this difference will be related to an increased likelihood of lower birth weight babies to mothers born in Pakistan¹⁰. Rates for Indian women are similar to white UK women¹¹.

Congenital abnormalities contribute more to the UK infant death rates among babies born to mothers born in Pakistan than they do to rates amongst babies born to mothers born elsewhere¹¹.

The other key issue amongst ethnic minority populations is where English is not the first language of the mother. This may result in communication issues if information about available antenatal care and support cannot be directly accessible for the mother in a way that she can understand and use.

Factors affecting infant death

4.4 Low birth weight

Low birth weight is probably the most important factor affecting infant death, i.e. those born weighing less than 2500 grams. A low birth rate can arise in two ways:

- When the baby is born pre term or prematurely (see 4.5).
- or
- When the baby is born full term but has inadequate foetal growth i.e. has Intra Uterine Growth Retardation, IUGR.

Around half of neonatal deaths nationally arise because the baby has a low birth weight¹². Babies born with very low birth weight i.e. under 1500 grams are at highest risk of dying.

Multiple births tend to result in low birth weight babies and so the chances of death are higher in multiple rather than singleton births. If babies who are part of a multiple birth do die then they are more likely to do so in the neonatal period⁶. Multiple births have increased in recent years particularly with developments in sub fertility treatments.

Birth weight is to some extent an indicator of the health of the parents⁵, and can highlight health inequalities in a population. This is because other reasons leading to inadequate foetal growth include:

- Smoking, which increases the risk by 3.5 times of having a low birth weight baby.¹³
- Diseases such as diabetes, hypertension and renal disease, particularly if these diseases are not well monitored throughout pregnancy.
- Other behaviours such as poor nutrition and maternal emotional stress.

There is a clear association between low birth weight and geographical deprivation¹⁴ for babies weighing 1500 - 2500g, but this relationship is not as noticeable in babies weighing under 1500g.

4.5 Prematurity/pre-term delivery

Pre-term delivery is the term used when a baby is born earlier than 37 weeks of pregnancy. This is a major factor linked to infant death as babies born pre-term are more likely to suffer:

- Respiratory distress syndrome caused by immature lung development. This complication affects male babies twice as much as female ones.¹⁵
- Infection - pre-term deliveries are less likely to have built up an immunity through receiving maternal antibodies, which starts from week 32 of pregnancy.
- Central nervous system complications.
- Feeding difficulties and so experience slow weight gain.

Factors contributing to preterm deliveries are:

- Pre term rupture of the membranes
- Foetal anomalies
- Infections
- Smoking by the mother
- Heavy physical work by the mother.

Some of these can now be managed better and so extend the pregnancy.

Common coding systems in use^a for categorising cause of death can understate the role of prematurity in infant death¹⁶, as other reasons are preferred in the main cause of death category. This lack of specificity is compounded by a reduction in post mortem examinations.

4.6 Infection

Bacterial infection is a cause of morbidity and mortality in newborn infants. The incidence is low but the consequences can be severe, particularly if the infection remains untreated¹⁷. The two main sources for infection are maternal, e.g. bacterium in the birth canal, or environmental e.g. low birth weight babies are more likely to receive assisted ventilation¹⁸.

4.7 Congenital abnormalities

Congenital abnormalities are significant factors in infant death. They are errors in the normal development of a foetus and are present from birth. Risk of them increase with increasing age of the mother. Their presence can also lead to premature delivery of the baby and thus a lower birth weight. With the development of antenatal screening, a limited number of abnormalities can be identified at an early stage in pregnancy and managed appropriately.

Congenital abnormalities arise for several reasons, including as a result of genetic imbalance (i.e. inherited) or following maternal illness e.g. viral infection such as rubella.

Consanguinity is the relationship between two people who are related to each other because they share a common ancestor. Such a relationship itself is not the cause of congenital abnormalities. It does increase the risk of very rare specific genetic disorders, as cousins are more likely to have the same genetic mutation that could result in such a disorder. Even so, according to birth incident data the risk of having a child with a congenital or genetic (including recessive) disorder is about 2%^b. This increases to 4% for first cousin couples, mainly because of the increased risk of the recessive disorders.¹⁹

Such relationships are described in the Bradford Infant Mortality Commission as culturally normal in that over 70% of marriages between Bradford Pakistanis have been described as being to a cousin and 55% to a first cousin..... Consanguinity per se is not the reason for a high infant death rate, rather that specific genetic inheritance within high risk consanguineous marriages may disproportionately affect the population's infant death rate.²⁰

^a such as the Extended Wigglesworth Classification which is in common use

^b Recessive genetic disorders can result in congenital abnormalities, They are associated with inheriting two copies of an identical genetic mutation; cousins are more likely to inherit an identical mutation because of sharing a common pair of grandparents, one of whom might carry that mutation. Having a child with a recessive disorder, means that the risk for the parents of further affected children rises to 1 in 4. This has implications for marriage between their close family members who also might carry that mutation.

4.8 Deprivation

Income levels influence how much families can choose their housing, diet, lifestyle, community location etc. Therefore a lower income reduces these choices and can lead to reduced opportunities to have a balanced healthy diet, live in good standard accommodation etc.

This can therefore lead to poorer maternal nutrition and possible maternal stresses. Education level is thought to be a minor influence and may be related to the likelihood of having less income and therefore the issues listed above in terms of maternal nutrition and stresses²¹.

Father's occupation has long been taken as a proxy for social class in national statistics. Nationally this shows that infant death is lowest in social class 1 and 2 and highest in social class 4 and 5. However the differences between these groups have reduced over the last 30 years.

Social class differences in infant death are more marked amongst babies living longer (i.e. over 28 days) and born over 27 weeks gestation⁶.

4.9 Maternal personal behaviours

Smoking in pregnancy is the behaviour most likely to contribute to a low birth weight for a baby born at full term. It is thought to account for 20-30% of all low birth weight babies in the USA¹³. There is thought to be a dose response relationship influencing birth weight i.e. the more cigarettes smoked the more likely it is that an infant will be lower birth weight, which in turn increases the chances of an infant death.

Nutritional status of a mother affects the birth weight of her child, and the risk in later life for that child of cardiovascular disease and non insulin dependent diabetes, especially if mother is also obese or excessively thin.²²

Eating a balanced healthy diet benefits before and during pregnancy by increasing reasonable weight gain in the foetus to achieve a normal birth weight as well as reducing the risk of perinatal death.²⁰

Routine dietary supplements should also be considered such as Folate which can reduce the likelihood of the foetus suffering congenital abnormalities, particularly neural tube defects e.g. spina bifida.

So for mothers today, both their present nutritional status and as a child is relevant. In other words especially those who had a poorer nutrition as a child need a good diet in pregnancy. This becomes a really significant challenge for the health of local women, given the increasing levels of overweight and obesity today.

Maternal breastfeeding can help reduce infant death. This is assumed to be a mixture of the nutritional element in breast milk and passing on of continued immunity factors to the child in the first few months of life.²³

Alcohol consumption can lead to a number of foetal abnormalities, particularly when the mother drinks to excess in the first trimester.

Misusing drugs can similarly lead to a number of foetal abnormalities, as well as leaving the baby suffering addiction to such drugs e.g. heroin, cocaine etc.

4.10 Services and access to them

The quality and availability of appropriate care is known to be a factor in the survival of babies born with life threatening conditions. In particular very low birth weight babies have better outcomes when delivered at specialist centres.¹³



Access to services and the availability of information is vital at four stages:

- Pre-conception
- Antenatal care
- Maternity
- Post-natal care.

Maternal health before conception is an important consideration, and thus her personal behaviours, see 4.9.

Accessing antenatal care as early as possible can reduce the chance of having a low birth weight baby. Factors such as diabetes and other diseases, smoking, drugs and alcohol use can be more effectively managed, as well as ensuring even weight gain is maintained. Any difficulties arising throughout the pregnancy can also be more quickly identified and hopefully managed.

5. Population and births in north Kirklees

The population of north Kirklees was 180,289 in 2004. This has increased by about 5000 since 1999. The profile of the population is slightly younger than that of England and Wales.

For the South Asian population across north Kirklees just under 32% are aged under 15 and 50% are aged 15 to 44. In contrast, 17% of the white origin population are aged under 15 and 40% are aged 15-44. The South Asian origin population therefore has a much younger profile than the non South Asian origin population, see figure 4.

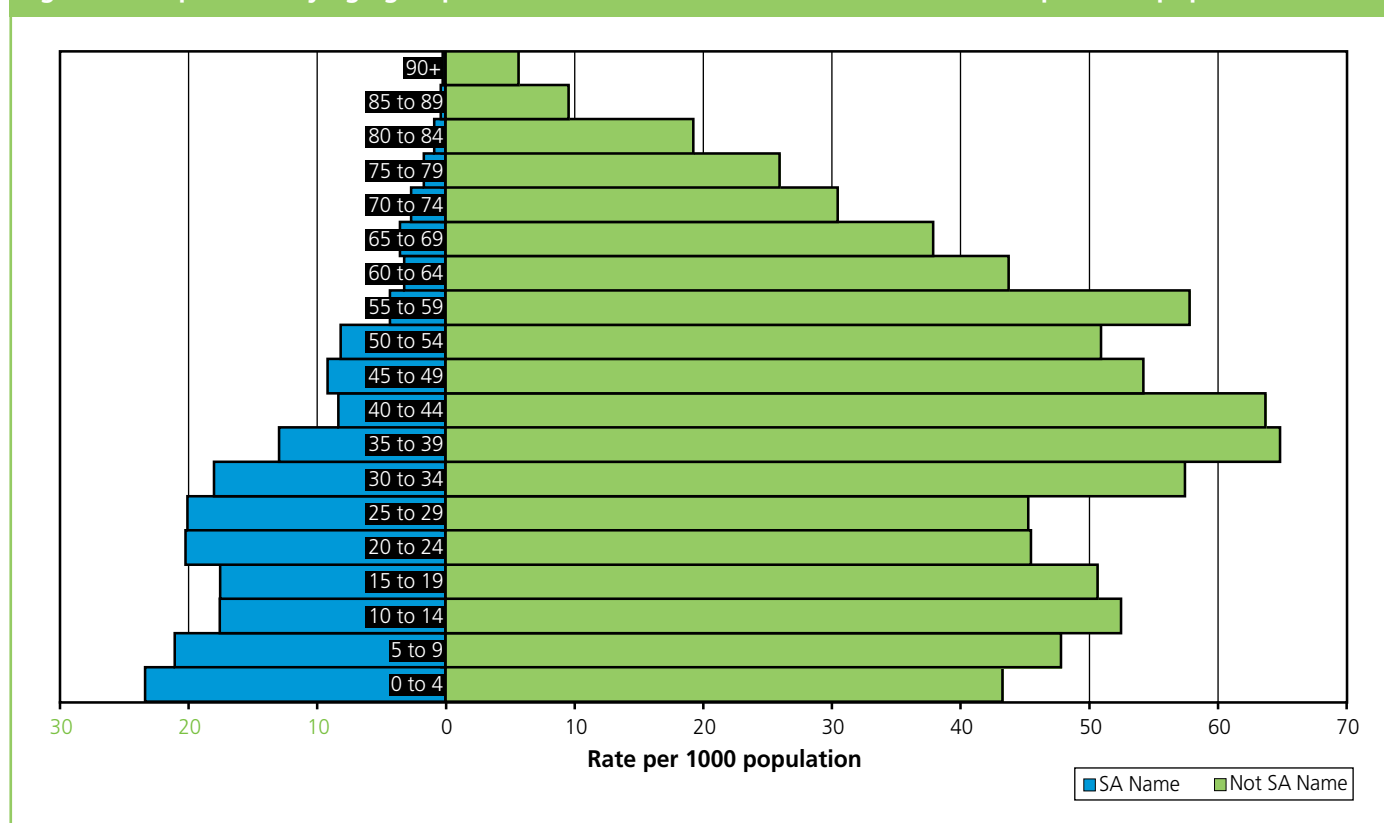
Table 1 – Population by Local Area Committee, north Kirklees, England and Wales aged 15 – 44 years 2006 %

| Area Committee | Under 15 yrs | 15-44 years |
|--|--------------|-------------|
| Batley | 22 | 45 |
| Birstall and Birkenshaw | 17 | 41 |
| Dewsbury | 23 | 44 |
| Mirfield | 16 | 37 |
| Spenningsdale | 18 | 41 |
| North Kirklees | 20 | 42 |
| England and Wales (ONS population estimate 05) | 18 | 42 |

Source: FHS population estimate December 2006, ONS

The number of births in north Kirklees localities has been constant for a number of years, around 2600, although the rate is higher than in England and Wales.

Figure 4 – Population by age groups and South Asian name, north Kirklees, 2005, per 1000 population



Source: FHS population estimate March 2005

Table 2 – Population by north Local Area Committees, north Kirklees, Kirklees by South Asian, non South Asian groups 2005 %

| Area Committee | Non South Asian | South Asian |
|-------------------------|-----------------|-------------|
| Batley | 64 | 36 |
| Birstall and Birkenshaw | 99 | 1 |
| Dewsbury | 69 | 31 |
| Mirfield | 99 | 1 |
| Spennings | 93 | 7 |
| North Kirklees | 81 | 19 |
| Kirklees | 86 | 14 |

Source: FHS population estimate March 2005

In 2004 there were 2602 live births with 882 (34%) live births to mothers of South Asian origin, higher than the overall proportion on the population. The proportion of babies born to South Asian origin mothers is increasing.

Table 3 - Annual general fertility rate per 1000 women aged 15-44 in 2004

| Area Committee | Live births | Per 1000 women |
|-------------------------|-------------|----------------|
| Batley | 630 | 79 |
| Birstall and Birkenshaw | 181 | 55 |
| Dewsbury | 963 | 79 |
| Mirfield | 175 | 49 |
| Spennings | 653 | 63 |
| North Kirklees | 2602 | 70 |
| England and Wales | 643026 | 59 |

Source: FHS population estimate April 2004, ONS

The fertility rate is highest in those areas with a high South Asian population, reinforcing the higher rate of births in mothers of South Asian origin.

North Kirklees localities are relatively deprived with half of their wards being in the top 15% most deprived wards in England. These wards are mainly in Batley and Dewsbury i.e. areas where the majority of the South Asian origin population live.



6. The local features and factors affecting infant deaths in north Kirklees between 2002-2005

6.1 Method

For each death occurring within the first year of life for babies resident in north Kirklees a detailed data set has been obtained. The items included in the dataset are listed in Appendix 1. Some data items are incomplete. Where appropriate, distinction has been made between data not recorded and missing case notes. Case notes were missing for several reasons. They were either untraceable within Dewsbury and District Hospital or the records were at other hospitals. These latter notes were not requested. The compilation of the dataset used in the analysis with the methodology and assumptions is outlined in Appendix 2.

In any given year in north Kirklees about 25 deaths occur in babies under one year. Therefore each death occurring in the period 2002 – 05 has been considered which has resulted in an adequate sample size of 106. The analyses include all cases apart from any analyses involving gestation where one case has been omitted. These analyses are therefore for 105 babies.

Features of infant deaths

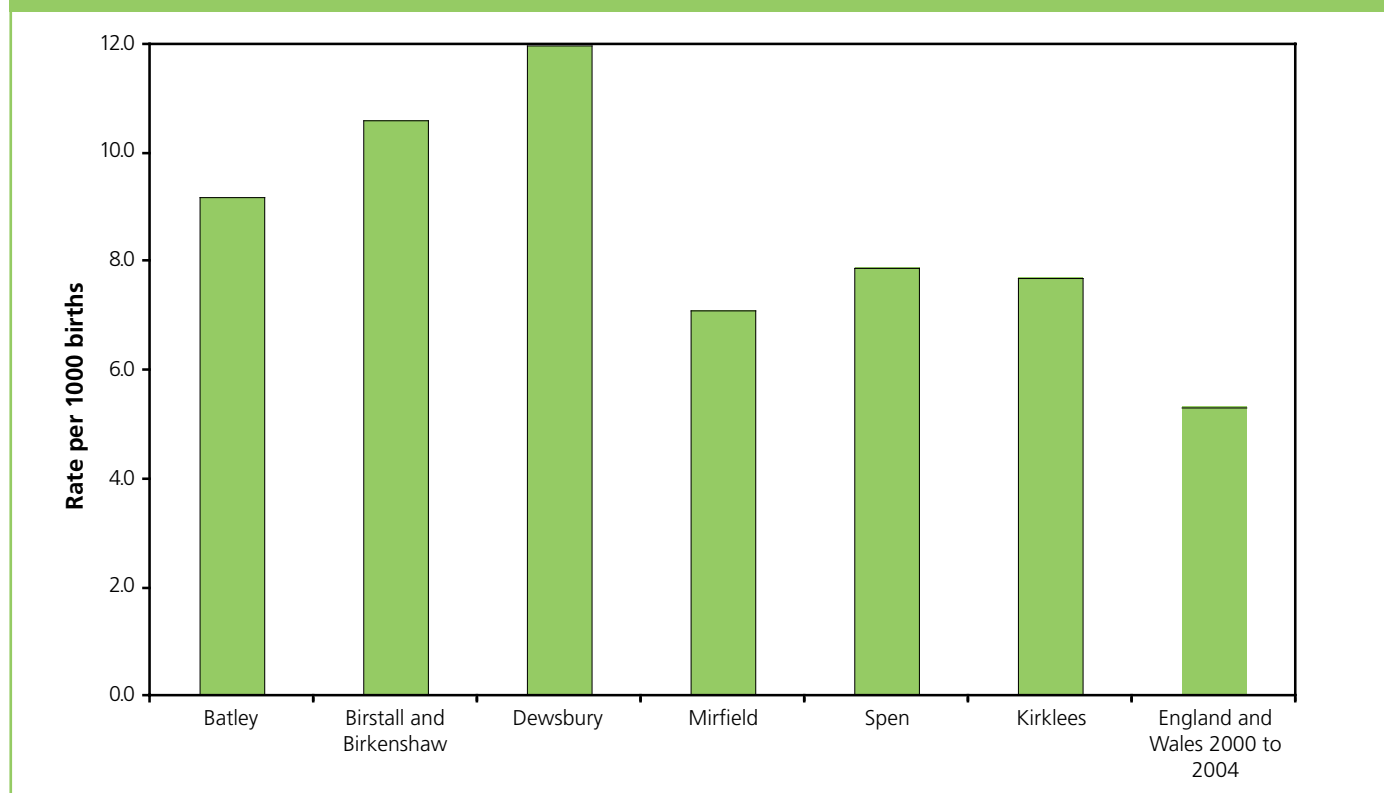
6.2 Deaths within north Kirklees

The deaths were spread across the communities of north Kirklees, with infant death rates as shown in figure 5.

It should be noted that particularly for Mirfield and for Birstall and Birkenshaw the actual numbers involved were very low with generally only one or two deaths occurring in any year. The average number of deaths per annum across north Kirklees between 2001 and 2005 was 25.

Nationally the rate is decreasing slightly, but in north Kirklees it continues to increase, see Figure 2.

Figure 5 – Infant Death Rate by Local Area Committee, Kirklees, England and Wales 2001-2005 per 1000 live births



Source: FHS population estimates, ONS

6.3 Ethnicity of the deaths, table 4

Of the deaths, 49% were to South Asian origin families, overwhelmingly of Pakistani origin. Overall in north Kirklees in 2005, 34% of live births were to women of South Asian origin. So babies of Pakistani origin mothers appear to have a higher risk of dying in their first year of

life than babies born to white mothers.

The infant death rate experienced by the non South Asian origin population in north Kirklees is also higher than the rate experienced by non South Asians across England and Wales, 8.6 deaths per 1000 live births, compared to 5.0 deaths per 1000 live births.

Table 4 Summary of key infant data items

| | South Asian Origin | | | | | | | | | |
|--|--------------------|-----------|------------|----------|-----------|-----------|------------|----------|------------|------------|
| | White | | Indian | | Pakistani | | Other | | Total | |
| | % | n | % | n | % | n | % | n | % | n |
| Overall | 47 | 50 | 8.5 | 9 | 41 | 43 | 3.8 | 4 | 100 | 106 |
| Gender | | | | | | | | | | |
| Male | 60 | 30 | 44 | * | 58 | 25 | 50 | * | 58 | 61 |
| Female | 40 | 20 | 56 | 5 | 42 | 18 | 50 | * | 42 | 45 |
| Birth weight (note 1) | | | | | | | | | | |
| Under 500g | 8.0 | * | 0 | 0 | 4.7 | * | 33 | * | 6.5 | 7 |
| 500-999g | 32 | 16 | 33 | * | 21 | 9 | 33 | * | 28 | 29 |
| 1000-1499g | 4.0 | * | 11 | * | 2.3 | * | 0 | 0 | 3.5 | * |
| 1500-2500g | 22 | 11 | 11 | * | 19 | 8 | 0 | 0 | 19 | 20 |
| Over 2500g | 34 | 17 | 44 | * | 53 | 23 | 33 | * | 43 | 45 |
| Gestational age at birth (note 1) | | | | | | | | | | |
| Under 24 weeks | 20 | 10 | 11 | * | 7.0 | * | 67 | * | 16 | 16 |
| 24-27 weeks 6 days | 20 | 10 | 33 | * | 14 | 6 | 0 | 0 | 18 | 19 |
| 28-31 weeks 6 days | 6.0 | * | 0 | 0 | 4.7 | * | 0 | 0 | 4.7 | 5 |
| 32-36 weeks 6 days | 20 | 10 | 22 | * | 16 | 7 | 0 | 0 | 18 | 19 |
| 37 weeks and over | 34 | 17 | 33 | * | 58 | 25 | 33 | * | 43 | 46 |
| Gestational age at death (note 1) | | | | | | | | | | |
| Under 24 weeks | 20 | 10 | 11 | * | 7.0 | * | 67 | * | 15 | 16 |
| 24 to 31 weeks 6 days | 26 | 13 | 33 | * | 14 | 6 | 0 | 0 | 21 | 22 |
| 32 to 40 weeks | 14 | 7 | 0 | 0 | 26 | 11 | 0 | 0 | 17 | 18 |
| Over 40 weeks | 40 | 20 | 56 | 5 | 53 | 23 | 33 | * | 47 | 49 |
| Length of Life | | | | | | | | | | |
| 0-24 hours | 34 | 17 | 22 | * | 21 | 9 | 75 | * | 29 | 31 |
| 1-6 days | 16 | 8 | 0 | 0 | 16 | 7 | 0 | 0 | 14 | 15 |
| 7-28 days | 20 | 10 | 22 | * | 23 | 10 | 0 | 0 | 21 | 22 |
| Over 28 days | 30 | 15 | 56 | 5 | 40 | 17 | 25 | * | 36 | 38 |
| Cause of Death | | | | | | | | | | |
| Congenital Abnormality | 24 | 12 | 44 | * | 51 | 22 | 50 | * | 38 | 40 |
| Prematurity | 40 | 20 | 44 | * | 21 | 9 | 50 | * | 33 | 35 |
| Infection | 8.0 | * | 0 | 0 | 14 | 6 | 0 | 0 | 9.4 | 10 |
| Respiratory | 6.0 | * | 11 | * | 9.3 | * | 0 | 0 | 7.5 | 8 |
| Other | 18 | 9 | 0 | 0 | 4.7 | * | 0 | 0 | 10 | 11 |
| Unknown | 4.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 1.9 | * |
| Multiple Births | | | | | | | | | | |
| Yes | 18 | 9 | 0 | 0 | 4.7 | * | 0 | 0 | 10 | 11 |
| No | 82 | 41 | 100 | 9 | 86 | 37 | 75 | * | 85 | 90 |
| Unknown | 0 | 0 | 0 | 0 | 9.3 | * | 25 | * | 5.0 | 5 |

Note 1: one case was missing all information on birth weight and gestational age. * number is less than 5

6.4 Gender, table 4

Across north Kirklees approximately 51% of the births are males each year, similar to nationally in 2004 and 2005. Nationally 125 males died compared to 100 females, whereas locally this was 130.

6.5 Birth weight, table 4, figure 6

The low birth weight birth rate per 1000 live and still births in 2004 in north Kirklees was 108 compared to a national rate of 79. This rate had reduced to 100 in 2005, still well above that national rate.

A clear relationship exists between low birth weight and younger gestational age at birth in these deaths. The majority of premature babies i.e. born at 32 to 36 weeks of pregnancy, weighed 1500 – 2500g and all the 'not viable' babies weighed under 1000g.

There were marked differences ethnically i.e. 47% of the babies born to women of Pakistani origin were of low birth weight, compared to 66% babies of white origin.

Given the link between prematurity and birth weight, then clearly this is not surprising i.e. white babies tend to be born very premature and thus low birth weight, compared to Pakistani origin babies, who are more often born at term.

6.6 Gestational age at birth, table 4

Over half of the babies who died were born pre-term i.e. under 37 weeks of pregnancy.

Of the white babies 46% were born under 32 weeks gestation, compared to 25% of Pakistani origin i.e. nearly twice as many of white origin were premature. The pattern of gestation also reflects the relationship between lower birth weight and earlier age at death.

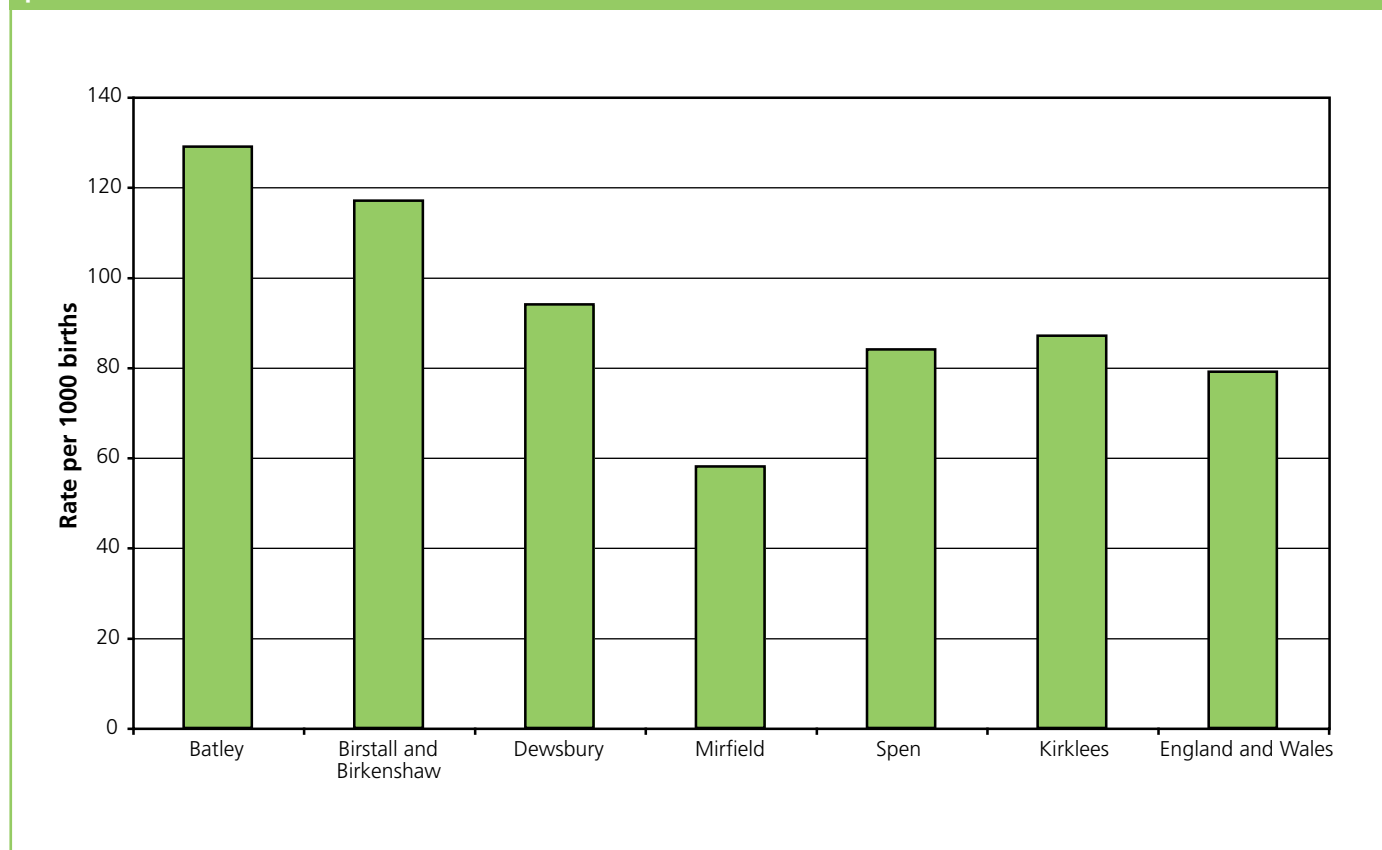
6.7 Age at death, table 4

All babies born not viable, i.e. under 24 weeks, died within their first week of life. Of those born at 24 – 27 weeks gestation over half died within their first week (10 of 19). Those babies reaching 32 or more weeks gestation at birth tended to live longer, with over half of them surviving more than 28 days.

For those babies born mature, 59% survived for more than 28 days and 24% died within 6 days.

So the chance of surviving longer was closely related to gestational age at birth and to birth weight, as expected.

Figure 6 - Low Birth Weight Rate (under 2500g) by Local Area Committee, Kirklees, England and Wales 2005, per 1000 live births



Source: FHS population estimates 2005, ONS

Factors affecting infant deaths

6.8 Multiple births, table 4

Of all the infant deaths 11% were a twin, compared to 2.9% nationally with no deaths being experienced in higher multiple births. Included in the twins were two births where both twins died. All of the twins dying in north Kirklees were born prematurely, with two not viable.

6.9 Cause of death, table 4

The main cause of death was identified and grouped into one of congenital abnormality, prematurity, infection, respiratory, other, or unknown. Due to the type of coding used, prematurity can be used as the primary cause where appropriate rather than a specific condition such as congenital abnormality. This can mask the underlying cause, but that can also be difficult to classify.

Of those dying of congenital abnormalities most (37 of 40) were born over 32 weeks gestation, of which 29 were born mature, i.e. at 37 or more weeks. Of the babies dying from congenital abnormalities 3 in 4 weighed over 2500gm (i.e. not low birth weight), which is also consistent with their gestation period. In 5 other cases congenital abnormality contributed to death and in 2 other cases congenital abnormality was present but did not cause or contribute to death. So overall about 46% of deaths were directly due or linked to congenital abnormalities.

Most babies dying of infections (8 out of 10) and all of those dying of respiratory disease were born over 32 weeks.

Of the babies dying of prematurity, 25 of 35 (71%) died at Dewsbury and District Hospital. Of the 40 babies dying of congenital abnormalities 19 (30%) died in Dewsbury and District Hospital and 14 (35%) died in Leeds, the local specialist neonatal centre.

None of the deaths were as a result of an accident.

The causes of death of infants dying in their first year in north Kirklees and their proportions reflects the main causes of death previously identified nationally.

6.10 Neonatal care

Half, (52%) of babies received neonatal care, 27 (26%) did not. This was not clearly recorded in 22% of cases. Of those babies born not viable, 5 (31%) received neonatal care, 8 (50%) did not. Of those babies who died over 40 weeks gestational age 26 (53%) received neonatal care, 14 (29%) did not.

When neonatal care is considered, 12 of the 35 (34%) babies dying of prematurity did not have neonatal care, with 8 unrecorded (23%). Of those dying of congenital abnormalities, 25% did not receive neonatal care, with 10 not recorded. The majority of children dying of infection, respiratory or other received neonatal care.



For some babies, neonatal care is planned or not, depending on the severity of the abnormality. The paediatric service actively treat a child unless a decision has been taken to withdraw neonatal care, either before birth or after assessment. It is not possible to derive particular conclusions about neonatal care from this level of analysis.

Maternal factors

6.11 Maternal age, table 5

Most babies (87%) who died had a mother aged between 18 to 34 years of age.

Across England and Wales 16% of deaths occurred to mothers aged over 35, compared to 10% locally. So mothers experiencing the death of a child in north Kirklees are more likely to be under 35 than nationally.

Given that young or old maternal age can be a factor in infant death, it would seem that this particular aspect is not a key factor for the deaths in north Kirklees.

6.12 Social class, table 5

The profession of the father recorded by ONS was used as a proxy for social class. Where this was missing, the occupation of the mother was used, although it should be noted that mother's social class can often understate their actual social class. The profile of social class in the infant deaths reflects the conclusion nationally that more deaths occur in classes IV and V than in classes I and II.^{6, 24}

Table 5 Summary of key maternal data – part 1

| | South Asian Origin | | | | | | | | | |
|---------------------------------------|--------------------|-----------|------------|----------|-----------|-----------|------------|----------|------------|------------|
| | White | | Indian | | Pakistani | | Other | | Total | |
| | % | n | % | n | % | n | % | n | % | n |
| Overall | 47 | 50 | 8.5 | 9 | 41 | 43 | 3.8 | 4 | 100 | 106 |
| Age of mother | | | | | | | | | | |
| Under 18 | 6.0 | * | 0 | 0 | 2.3 | * | 0 | 0 | 3.8 | * |
| 18-25 | 38 | 19 | 44 | * | 47 | 20 | 25 | * | 42 | 44 |
| 26-34 | 48 | 24 | 44 | * | 42 | 18 | 50 | * | 45 | 48 |
| 35-39 | 6.0 | * | 11 | * | 9.3 | * | 25 | * | 8.5 | 9 |
| 40 and over | 2.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 0.9 | * |
| Social class | | | | | | | | | | |
| I - Professional | 2.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 0.9 | * |
| II - Managerial and Technical | 12 | 6 | 11 | * | 2.3 | * | 25 | * | 8.5 | 9 |
| IIIN - Non-manual skilled occupations | 10 | 5 | 33 | * | 14 | 6 | 25 | * | 14 | 15 |
| IIIM - Manual skilled occupations | 20 | 10 | 11 | * | 11 | 5 | 0 | 0 | 15 | 16 |
| IV - Partly skilled occupations | 16 | 8 | 44 | * | 58 | 25 | 25 | * | 36 | 38 |
| V - Unskilled occupations | 14 | 7 | 0 | 0 | 4.6 | * | 0 | 0 | 8.5 | 9 |
| Other | 6.0 | * | 0 | 0 | 2.3 | * | 25 | * | 4.7 | 5 |
| Unknown | 20 | 10 | 0 | 0 | 7.0 | * | 0 | 0 | 12 | 13 |
| Gestational age at booking | | | | | | | | | | |
| Under 16 weeks | 38 | 19 | 56 | 5 | 35 | 15 | 25 | * | 38 | 40 |
| 16-24 weeks | 16 | 8 | 22 | * | 19 | 8 | 25 | * | 18 | 19 |
| Over 24 weeks | 2.0 | * | 0 | 0 | 11 | 5 | 0 | 0 | 5.7 | 6 |
| Not booked | 4.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 1.9 | * |
| Not known | 40 | 20 | 22 | * | 35 | 15 | 50 | * | 37 | 39 |
| Smoking | | | | | | | | | | |
| Yes | 44 | 22 | 0 | 0 | 0 | 0 | 0 | 0 | 21 | 22 |
| No | 32 | 16 | 78 | 7 | 67 | 29 | 50 | * | 51 | 54 |
| No data | 2.0 | * | 11 | * | 9.3 | * | 0 | 0 | 5.7 | 6 |
| No notes | 22 | 11 | 11 | * | 23 | 10 | 50 | * | 23 | 24 |

* number less than 5

6.13 Gestational age at booking, table 5

The gestational age at booking is important as the earlier this happens, the greater chance of detecting any problems early and managing them. This was unknown in 37% of cases. Where it was known, over half of mothers booked at less than 16 weeks. However of those booking over 24 weeks the majority were of Pakistani origin. Where understanding of English was also known, only 31% non-English speaking mothers booked less than 16 weeks compared to 60% of English speaking mothers.

6.14 Smoking, table 5

This was only recorded in 71% of cases. Of those deaths where the smoking status of the mother is known:

- 29% smoked and all were of white origin
- 60% of white mothers smoked

Smoking by Pakistani women is associated with a cultural taboo, stigma and non-acceptance by the Pakistani community as a whole.²⁵ Therefore any Pakistani women who do smoke may feel reluctant to declare it at antenatal booking. The smoking status data in this group is incomplete or not robust.

Health behaviours of women aged 18-44 years 2005 %

| Indicators | Bat | BB | Dews | Mir | Spen | Kirklees |
|-----------------------------|-----------|-----------|-----------|-----|-----------|-----------|
| Obese or overweight | 42 | 35 | 47 | 30 | 45 | 41 |
| Smoking daily | 21 | 21 | 24 | 14 | 21 | 20 |
| Smoking at birth of child * | 31 | 27 | 34 | 18 | 23 | 23 |

Bold is worse than Kirklees average.

* Of non South Asian origin in 2007

The table above shows the areas with the highest infant deaths also have the highest rates of being overweight, and smoking, especially at the delivery of their child.

6.15 Alcohol and drug consumption

This aspect was poorly recorded, i.e. only 62% recorded. Of these, only 10 (15%) indicated that they consumed alcohol, the majority at a low level. One case was drinking to harmful levels and two cases had been taking heroin. So, overall neither alcohol nor drugs seem to be significant in infant deaths locally.

6.16 Consanguinity, table 6

This was not recorded in 79% of cases, which makes any conclusions hard to derive. Of those recording that were first cousin marriages, all were of South Asian origin.

6.17 Place of death, table 6

Of the not viable babies 15 (88% of not viable) died in Dewsbury. Of the 49 (47%) reaching over 40 weeks gestational age, 7 of them died at home. Of the others 25 (51%) died in Dewsbury and District Hospital and 15 (31%) in Leeds.

6.18 Family history of congenital abnormality

For 45% of babies this was unknown. However 17 (16%) babies had a family history of congenital abnormality in a sibling, of whom 14 (82%) of Pakistani origin. Of these 17, 15 babies died of congenital abnormalities.

6.19 Maternal diabetes

Nationally 2 to 5% of pregnancies involve women with diabetes, which would require appropriate antenatal support to minimise the impact on the foetus. Locally, this aspect was poorly recorded with 35% cases unknown. However at least 5.7% of women whose child died had some form of diabetes, half being of white origin i.e. same as for all deaths. So diabetes itself is a factor.



Table 6 Summary of key maternal data items – part 2

| | South Asian Origin | | | | | | | | | |
|--------------------------------------|--------------------|-----------|------------|----------|-----------|-----------|------------|----------|------------|------------|
| | White | | Indian | | Pakistani | | Other | | Total | |
| | % | n | % | n | % | n | % | n | % | n |
| Overall | 47 | 50 | 8.5 | 9 | 41 | 43 | 3.8 | 4 | 100 | 106 |
| Consanguinity | | | | | | | | | | |
| Yes | 0 | 0 | 22 | * | 37 | 16 | 0 | 0 | 17 | 18 |
| No | 10 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 4.7 | 5 |
| No data | 64 | 32 | 66 | 6 | 42 | 18 | 50 | * | 55 | 58 |
| No notes | 26 | 13 | 11 | * | 21 | 9 | 50 | * | 24 | 25 |
| Previous pregnancies | | | | | | | | | | |
| No previous pregnancies | 22 | 11 | 11 | * | 14 | 6 | 0 | 0 | 17 | 18 |
| All live and OK | 26 | 13 | 44 | * | 33 | 14 | 0 | 0 | 29 | 31 |
| Including miscarriages and/or deaths | 18 | 9 | 44 | * | 37 | 16 | 50 | * | 29 | 31 |
| Congenital abnormalities and living | 4.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 1.9 | * |
| Including termination of pregnancy | 6.0 | * | 0 | 0 | 4.6 | * | 0 | 0 | 4.7 | 5 |
| No data | 4.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 1.9 | * |
| No notes | 20 | 10 | 0 | 0 | 12 | 5 | 50 | * | 16 | 17 |
| Place of death | | | | | | | | | | |
| Dewsbury and District Hospital | 66 | 33 | 56 | 5 | 53 | 23 | 50 | * | 59 | 63 |
| Leeds (LGI or SJH) | 16 | 8 | 22 | * | 33 | 14 | 0 | 0 | 23 | 24 |
| Other hospital | 2.0 | * | 11 | * | 2.3 | * | 50 | * | 4.7 | 5 |
| Elsewhere | 4.0 | * | 0 | 0 | 0 | 0 | 0 | 0 | 1.9 | * |
| Home | 6.0 | * | 11 | * | 9.3 | * | 0 | 0 | 7.5 | 8 |
| Not known | 6.0 | * | 0 | 0 | 2.3 | * | 0 | 0 | 3.8 | * |

* number less than 5

6.20 Screening

During the period covered by the analysis several antenatal screening programmes have been approved nationally. These have been implemented in stages locally. For all forms of screening it has been hard to identify what tests have been offered and which have been taken up. However the hospital has implemented a more effective recording of offer and uptake since 2006. Despite this, uptake of the triple test, a blood test used to detect Down's syndrome, varies between 25 and 40%, with a particularly low uptake within the South Asian community

(less than 1%). The infectious disease screening programme uptake also varies, between 85-90% for HIV to 100% for rubella. This programme has identified a number of Hepatitis B cases.

6.21 Understands English

This item was poorly recorded i.e. 22% of cases had maternal notes missing and 37% of cases did not have the item recorded. Of these unknown cases 32 (51%) described themselves as white/ British, 22 (35%) as Pakistani, and 7 (11%) Indian. Of the 45 cases where the

information was recorded 13 did not understand English, 11 of whom were Pakistani. It was unclear whether these mothers received appropriate language assistance to support them throughout their care. However the poor data collection prevents any conclusion being reached.

6.22 Rickets

Rickets does not cause death. But it is important to note as a marker of nutrition, in that it is a disease caused by vitamin D deficiency, and is more common in the South Asian population because of dietary habits and lack of exposure to sunlight. It is particularly common in children, breastfed babies, pregnant and lactating women and adolescents. NICE has produced a "Consultation Draft" on Maternal and Child Nutrition²⁶ which recommends that all pregnant and breastfeeding women and particularly those who have limited exposure to sunlight and/or have dark skin, should be given vitamin D supplements.

About one new case of florid rickets is diagnosed every week by paediatricians in Dewsbury.

7. Summary of analysis

Having analysed a range of variables linked to features and factors affecting infant death it is clear that some are influencing the situation locally more than others.

The following locally are similar to those nationally:

- Gender of baby – consistent with national pattern expected
- Age of child at death – consistent with national pattern expected
- Cause of death – consistent with national causes of infant death.

The following national factors are not a local risk factor:

- Age of mother – very few deaths occurred in young or old mothers who are the groups at greatest risk
- Social class – the pattern amongst deaths locally mirrors the profile of north Kirklees i.e. deaths were not particularly more frequent in lower social classes than the rest of north Kirklees.

Key infant features and factors

- The rates for both non South Asian and Pakistani populations in north Kirklees were higher than nationally.
- Half were of South Asian origin, mainly Pakistani, compared to 1 in 3 births being of South Asian origin.
- Over half were born prematurely i.e. before 37 weeks of gestation.

- Over half were of low birth weight, which is linked to prematurity.
- Twice as many white babies, compared to Pakistani, were born before 31 weeks gestation. So white babies tended to have prematurity as their cause of death whereas Pakistani had congenital abnormality, and were more likely to be born near term.
- The cause of death is also related to the age of birth, as prematurity is a cause of death. This and congenital abnormality were responsible for over 2 in 3 of the deaths. Of those dying of congenital abnormality only 1 in 4 were premature.
- Multiple births was far higher locally than nationally and mainly of white origin.

Key maternal features and factors

- Very few were at the extremes of age of motherhood i.e. under 18 or over 40 years.
- Sibling history of congenital abnormality existed for 1 in 6 of the babies, mainly in Pakistani families.
- 1 in 4 of all mothers booked later than 16 weeks, thus delaying the possibility of early identification of relevant factors to manage.
- Screening for infection was high but for certain genetic screening was extremely low for South Asian mothers.
- Smoking was significant but alcohol and drug use was not.

So some features and factors clearly influenced the rate of infant death and specifically contribute to the rate locally. These are described in detail below.

7.1 Ethnicity of the infant deaths

Nationally, a key feature of infant death is that some ethnic groups have higher rates of infant death.¹⁰ One of these groups is Pakistani. So any population including a high proportion of Pakistani origin babies will have a higher rate of infant death. However, compared to other areas with a similar proportion of their population of Pakistani origin, the rate of infant death in north Kirklees is higher.

The proportion of the local population of Pakistani origin is also increasing, especially younger groups compared to the white origin population. Local fertility rates are higher than nationally, particularly in Batley and Dewsbury, where the majority of the South Asian population live. So, given the rising proportion of Pakistani origin births and if they continue to experience similar rates of infant death to those over the last 5 years, infant death may well continue to rise overall.

It is very important to note that the non South Asian rate was over 50% higher than that nationally i.e. 8.6 vs. 5.

So the difference experienced in north Kirklees infant

death rates over those in England and Wales is only partially due to the demography of the local Pakistani population.

7.2 Congenital abnormalities

Babies of Pakistani origin were twice as likely to have congenital abnormalities recorded as cause of death, similar to nationally. This is because they were also nearly twice as likely to be born near term and so were not premature or of low birth weight. Of those families having a previous child with congenital abnormality i.e. having a higher risk of parental genetic mismatch, most were Pakistani. Given the later gestational age of birth of Pakistani babies, then it is not surprising that virtually all with such a sibling died of congenital abnormality. Also, it is also important to note that locally there are a higher proportion of congenital abnormalities in living children of Pakistani origin.

Unfortunately the recording of congenital abnormality was inconsistent throughout antenatal care, delivery and death for further analysis to be possible at this stage.

7.3 Prematurity of the infant deaths/ low birth weight

As expected gestational age at birth was linked to birth weight i.e. the younger the birth, the lower the birth weight. Overall, more babies are born with low birth weight locally than the national rate. Locally, babies of white origin were nearly twice as likely as those of Pakistani origin to be premature and thus of low birth weight, which also links to 3 in 5 of white mothers smoking.

Low birth weight is linked to deprivation, and north

Kirklees has high levels of deprivation. Birth weight is probably linked to the higher rates of smoking and poor diet in deprived groups, which also increases the risk of diabetes and other diseases in the mother.

Better recording of key factors would therefore help to understand which factors may be contributing to low birth weight and prematurity, in all local births. This would also enable education of mothers regarding the risk factors and possible obstetric care options.

7.4 Booking and uptake of antenatal care

Although the levels of recording varied, it appears that non-English speaking mothers tended to book later than English speaking mothers. There was wide variability in screening between being high for infectious diseases but very low for genetic screening of mothers of South Asian origin. The opportunities for early antenatal care and understanding the role of screening clearly is important to communicate to all mothers. This may also reflect a reluctance to take certain screening up, if the only intervention offered or understood is termination of pregnancy.

The recording of diabetes and support for women with diabetes has been revised during the period of the analysis. Since 2004 a more comprehensive assessment is made to ensure that all women are identified as early as possible and receive appropriate support. This has also resulted in better recording of data.

7.5 Multiple births

This was four times higher locally and mainly of white origin. So it remains important for early detection of twins and individual risk behaviours in their mother i.e. smoking etc.

7.6 Data recording

A number of factors which the study wished to consider could not be analysed as data availability or collection was poor, see table 7 in Appendix 2. A number of case notes were unavailable or located at other hospitals.

However of particular concern was the lack of recording of several key data items, particularly smoking status, understanding English and consanguinity. It is known however, that the paediatricians ask about consanguinity in all situations where the child has an inherited disorder.



8. Conclusions

Infant death will still occur within the population, but there are clear local action points to reduce the current increasing local rate.

8.1 Supporting good maternal and family health

This was a key recommendation of the Annual Health Report in 2003²⁷ and was reiterated in the Annual Health Report in 2005¹. It cannot be understated in its importance.

The personal behaviours of mothers profoundly affect the health of their unborn child and the health of their existing children into their own adulthood. Key behaviours are:

- Not smoking using the whole family approach e.g. Smoke Free Home initiative, not just the potential mother, and reassuring South Asian mothers that they can receive a fully confidential service.
- Having good balanced nutrition²⁸ including the importance of reducing obesity and being underweight. So ensuring that the appropriate levels of folic acid, iron and vitamin D are included in a woman's diet via supplements if necessary. Ideally, all South Asian children and women should have regular vitamin D supplements particularly when pregnant or breastfeeding²⁶. The easiest way to achieve this would be to fortify a common food such as milk, as it is done in the USA or flour as in Canada or chapatti flour.
- Stopping alcohol consumption and/or drug taking.

After birth

Key information and support is offered to all parents after birth, e.g. on breastfeeding, diet, reducing accidents and about appropriate benefits.

Smoking by the family significantly affects the health of the children so this remains a key priority for all services to support smoking families.

8.2 More awareness of genetic conditions which may cause infant death

Locally we need to understand better the impact genetics can have on future generations particularly in managing increased risk (see section 4.4 Congenital abnormalities). This may include access to pre-conception genetic counselling for some families, e.g. those with a previous congenitally abnormal child.

It is important for communities locally to fully understand the role of consanguinity in contributing to congenital abnormalities in children of such relationships, i.e. it doubles the risk to 1 in 25 of births. Of much greater significance is the much higher risk of 1 in 4 births in families where there is already a congenitally abnormal child and the implications for consanguineous relationships in the close relations of such families.¹⁹ So in summary marriage within families can be over exaggerated as a factor in congenital abnormality, except for very few where congenital abnormality has occurred.²⁰

Further recognition is also required in understanding the role of congenital abnormality in infant death, and the implications and impact it has on children and their families who live with resulting disabilities locally.

It is recommended that organisations locally contribute to the establishment of the proposed regional congenital anomalies register as a priority.

8.3 Good antenatal care is accessible and accessed

So the importance needs to be known within all communities. Key issues are:

- Accessing antenatal care as soon as possible ensures that any factors arising can be well managed throughout the majority of the pregnancy. This is supported by the offer of the various National Screening Programmes²⁹ at relevant stages in antenatal care.
- The management of diabetes, particularly gestational, assessment of any genetic inheritance issues and multiple pregnancies is particularly important as these carry higher risks of suffering infant death.



- Locally, services need to ensure that they can also respond and support women whose first language may not be English. This will include provision of materials and information in an accessible way e.g. via link workers, and material devised in such a way that people who are not familiar with English and/or have a poor educational attainment are not disadvantaged.
- So, the opportunity locally to be able to learn English should continue to be a priority.
- Work locally should focus on ensuring all women are aware of and fully understand the programmes available and are able to make an informed decision about uptake.
- Access to support for healthy eating including supplements and not smoking

8.5 Data collection and recording

A range of analyses have not been possible to carry out because of the quality and availability of data. Some of these data items may be a factor in infant death locally, but at this stage no conclusions can be reached. Data items to be collected need to be clearly defined, incorporated in recording forms and computer systems and support given to staff, if necessary, to ensure full capture occurs in a timely and accurate way. Consideration of a minimum data set for antenatal care should be developed, implemented and closely monitored for completion.

Mid Yorkshire Hospitals NHS Trust should consider how they run their case note documentation, storage and retrieval systems, and how information is recorded within them and/or within electronic systems now becoming more available, as improvements in recording and keeping are required.

Locally the recommendations of the *'Working Together to Safeguard Children'*³⁰ guide must be adopted, particularly the recommendations relating to child death review processes. This should link into the existing process for reviewing all infant deaths in Mid Yorkshire Hospitals NHS Trust, see Appendix 3, and ensure that lessons are learnt and systems and processes improved in future.

8.6 Support for further research

Particular factors are known to contribute to infant death. In a number of areas further research is required to assess the impact, both locally and at a national level, particularly about factors which can lead to low birth weight and/or pre-term delivery. Any valid research proposals to inform these areas should be seriously considered for support.

9. Key recommendations for action

- 9.1 Disseminate the results of this report widely to ensure a public understanding of why Dewsbury, Batley and Spen have increasing infant deaths.
- 9.2 Continue to promote health behaviours in women of reproductive age but specifically focus on:
 - Not smoking, before, during and after pregnancy
 - Healthy eating, especially where planning to be pregnant
 - Not drinking alcohol
 - Reducing unintended pregnancies
 - Reducing the incidence of rickets and neural tube defects through dietary supplements.
- 9.3 Ensure the messages regarding what care is available before, during and after pregnancy are easily understood by all potential and existing mothers and their families.
- 9.4 Raise awareness of the impact and size of congenital abnormalities locally, especially in the Pakistani communities.
- 9.5 The recording of health care must be improved by Mid Yorkshire Hospitals NHS Trust, so that appropriate care can be seen to be offered.



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Appendix 1

Infant deaths in north Kirklees

Dataset

| Variable name* | Record Reviewed | Details / Issues |
|--|-----------------|------------------|
| Mothers details | | |
| Mother's hospital number | | |
| Mother's postcode | | |
| Child's NHS number | | |
| Mothers age at birth of child | | |
| Ethnic group of mother | | |
| Country of birth | | |
| Religion | | |
| Mother understands English? | | |
| Parents country of origin | | |
| Consanguineous marriage (yes / no) | | |
| Type 1 or Type 2 diabetic (state) | | |
| FH of congenital disabilities? | | |
| Personal behaviours | | |
| Smoking status | | |
| Alcohol consumption | | |
| Known domestic abuse (yes / no) | | |
| Antenatal details | | |
| Gestation at booking | | |
| Antenatal contacts (list including FTA) | | |
| Screening uptake | | |
| No of previous pregnancies | | |
| Number of babies in this pregnancy | | |
| Delivery details | | |
| Date of delivery | | |
| Time of delivery | | |
| Place of delivery | | |
| Birth order of baby | | |
| Mode of delivery (ND / CS) | | |
| Breach presentation (yes / no) | | |
| Birth details | | |
| Gestation | | |
| Sex of baby | | |
| Birth weight | | |
| Abnormalities (list as per classification) | | |
| Fathers Occupation | | |

| | | |
|--|--|--|
| Social class (derive from above) | | |
| Breastfeeding Initiated? | | |
| Neonatal details | | |
| Time spent on neo natal unit | | |
| Time spent on special care | | |
| Reason for time spent on neonatal unit or special care (diagnosis) | | |
| Post natal details | | |
| Significant post natal issues | | |
| Details of death | | |
| Cause of death | | |
| Date of death | | |
| Time of death | | |
| Place of death | | |
| Age at death | | |

* Grey shaded cells indicate data that is not necessarily needed in the analysis but is a way of retrieving the necessary information

Appendix 2

Data collection

North Kirklees PCT had experienced around 25 – 30 infant deaths each year since 2000. Although this was a relatively small number, the infant death rate locally has nearly twice that of England and Wales. Therefore to obtain meaning from any analysis several years data was requested. Based on the availability of data the final cohort covered deaths in 2002 – 2005 inclusive. During this period 112 babies died during the first year of their life who were resident in north Kirklees.

Defining the data set

Early in the work conversations were had with the NHS Information Services in Bradford, who were involved in work with the Infant Mortality Commission. The investigation in north Kirklees was never intended to replicate the Bradford work. However, it was recognised that with consideration the work in the two locations could support each other.

Within the analysis in north Kirklees we were keen to incorporate various aspects of antenatal activity, which we considered could impact on delivery and subsequent progress. The DPH's Annual Report 2003²⁴ had focused on children and identified the significance of pre-conception and antenatal activities by the mother, which can impact on the unborn child.

The final data set therefore reflected a lot of data items being analysed in Bradford, but included some items not under consideration there. We carried out manual data collection and did not rely solely on electronic sources as was the case in the Bradford study. Our proposed proforma was shared with Bradford who helpfully suggested some additions and alterations which were incorporated.

The final data set is indicated in Appendix 1. Several items are a means of collection, e.g. mothers case note number, and were not used in the final analysis.

Maintaining confidentiality

Throughout the work anonymity was a prime consideration. Apart from the work to derive data from case notes the analysis has not required the use of patient identifiable data. Cases were allocated a study reference number and the key to the patient details has been stored away from the analysis work. The work in establishing this process and obtaining access was carried out with the full support of the Caldicott Guardians in North Kirklees PCT and in Mid Yorkshire Hospitals NHS Trust. (MYHT)

Time period

At the outset the intention had been to analyse data from 2001 to 2005 inclusive. However it was soon apparent that the ONS data available from the local Health Informatics service in electronic form, from 2001, was unreliable and so this year was dropped.

Sources of data

Various sources of data were used to compile the data set analysed. These were:

1. Annual birth & death extracts

These are provided by the Office for National Statistics (ONS). The first trawl of these extracts searched for all deaths where the person was aged under 1 year and at time of death had a usual address in north Kirklees. This was then matched with the birth data for that child. Data was extracted on the basis of date of death, not of registration. This therefore does not correlate exactly with cases used to derive nationally published Infant Mortality Rate (IMR) figures, which use date of registration as the year indicator.

2. Child Health System

A similar query was carried out in the Child Health System in use across north Kirklees, to identify all children who died within their first year of life within this database. It was recognised that this could be an incomplete set of data, but should cover all children deemed to have a usual address in north Kirklees. The computer system used by Child Health Services (CHS) has been the same throughout the study period. The intention was to use this set of data to compare with the ONS extracts, as some concern had arisen in the recording of data around the boundaries, particularly with Bradford PCTs, and less so with Wakefield PCTs. This system also recorded certain data items not readily available from the ONS extracts.

3. Hospital records in Dewsbury and District Hospital (part of MYHT)

For all children born in Dewsbury and District Hospital their delivery notes were identified and when found were also considered and contributed further details to the data set. Children not born at Dewsbury and District Hospital were also checked on the Master Patient Index in case they had subsequent case notes generated and if this was the case they were also retrieved and information gathered where possible.

Each child's' mother was also identified and her case notes were retrieved if possible. This provided more information about antenatal care and delivery details, again adding to the defined data set.

4. Health Visitor records

These were also checked and where available obtained to complement and and/or check data already collected. Health Visitor data sets were also checked to ensure that no other children had died in their first year and had not been identified through the other sources.

For those mothers receiving antenatal care at other hospitals and/or delivering elsewhere no attempt was made to locate the case notes. This was because some data was available via ONS and the other aspects focused on antenatal care locally, which would be less relevant for those receiving care elsewhere.

Data compilation

A number of children with an address in north Kirklees were born and/or died outside the area. This situation arose for a number of reasons, the main one being access to specialist neo-natal care which is generally provided in Leeds for residents in north Kirklees. Other units had also been utilised. Details for all of these children were still checked within the MYHT Patient Administration System (PAS), primarily to identify the mother and to obtain these notes if she had been receiving antenatal care locally. For some of these children no local hospital records were available but the ONS data set provided sufficient information to make it relevant to retain these children in the analysis.

The focus throughout the analysis has been on what we can do locally to reduce the rate of infant death and so for children experiencing birth and/or death elsewhere these factors may be less applicable anyway.

Throughout the collection of data, apart from when checking the children's details and their mothers details, the data was referred to by NHS number and name and full address were removed almost immediately from the data set established. Subsequently a local numbering system was applied to the cases which made reference easy for those carrying out the analysis but meant there was no direct reference to individual patient details.

Data validation

Comparison of the ONS data set with the same analyses from the Child Health system showed a few differences. These were studied and all but one were resolved. Three of the cases identified by the Child Health system but not by ONS were children usually resident in north Kirklees who had been killed in two separate accidents abroad. These cases were not added to the data set. The comparison also indicated a few differences with dates of birth and death and a number of post code differences.

Post code details were resolved by obtaining the post code for the address given and using that, which tended to be the one that was recorded in the Child Health system. Discrepancies with dates of birth and death were resolved

by accessing the hospital PAS system, as all of these cases had activity in Dewsbury and the dates recorded in the case notes were taken. These were not always the same as the ONS data set. No checks were made for children born in north Kirklees, living elsewhere and dying within their first year.

The various data sources identified above were used to populate as many of the fields in the agreed data set as possible. Where information was duplicated this was used as a check and a refinement of that recorded. This led to a range of queries, particularly concerning the cause of death. The majority of these were with reference to primary cause of death and other reasons, in terms of the order they had been listed in the case notes compared to on the death certificate. These were resolved by a Consultant Neonatologist looking at the data and generally deferring to the ONS order. This checking process did however indicate a number of other items relevant to the overall data set, which were followed up.

No formal validation and cross checking was carried out, but the data was sense checked and any queries were followed up with as many of the data sources as possible. This resolved a number of data entry errors.

Cases excluded

Three of the cases were of early gestation (under 20 weeks) and a termination was being carried out, but they had been recorded as a live birth. After some debate these were excluded from the analysis.

At the end of the data collection process the majority of data items had been obtained if available. Five cases remained with very little data, as the cases had not yet been registered and the case notes could not be obtained. Other than knowing the death had occurred no other information was available from ONS and no more could be collected. It was decided that these 5 cases should be removed from the analysis. All of them were in 2005.

One ONS reference to a death at Dewsbury and District Hospital had no other details. The other data sources did not identify any other child which this could be. It was therefore excluded.

No duplications were found after considering the various sources of data.

The final data set was therefore 106 cases.

Comments

The data collection and reconciliation process was extremely time consuming. Electronic data via ONS and the Child Health System was made available relatively quickly. The particular time consuming elements were in referring to hospital case notes. Although MYHT were extremely helpful in searching for and obtaining what case notes they could, several trawls through their tracing service had to be made to obtain some sets of notes.

The actual reading of the case notes was extremely time consuming as there was much surplus information within the notes, the quality of handwritten note taking varied and there was little systematic filing within the notes e.g. chronological order. This was particularly difficult when searching the mother's records, particularly if they had had several births. It was often hard to distinguish which information was relevant to which birth.

Case notes from 2002 had been microfiched. Arrangements to access these were complex, but eventually resolved. Finding a way through the information fished was time consuming and difficult.

Case notes from 2003 were particularly hard to obtain as they were in the process of being sorted and sent for microfiching. This held up the analysis for some months.

Recoding

To enable easier analysis of some of the data items, they were categorised. This consisted of coding and re-categorising. A new data item was then derived. This re-categorisation included:

| ITEM | HOW CATEGORISED |
|--------------------------|---|
| Age at death | Up to 24 hours, 1-6 days, 7-28 days, Over 28 days |
| Cause of death | Congenital abnormality, Prematurity, Respiratory, Infection, Other, Unknown |
| Age of mother | Under 18, 18-25, 26-35, 36+ |
| Screening Tests | Routine Bloods, Ultrasound, Anomaly scan, Triple test |
| Previous pregnancies | All live and ok, including miscarriage and/or death, congenital abnormality and living, including TOP |
| Gestational age at birth | Under 24 weeks, 24-27 weeks 6 days, 28 weeks- 31 weeks 6 days, 32-36 weeks 6 days, 37 weeks and over |
| Birth weight | Under 500 grams, 500-999 grams, 1000-1499 grams, 1500-2500 grams, Over 2500 grams |
| Social class | I, II, IIIN, IIIM, IV, V and other |

NB Congenital abnormality was further categorised in to one of 3 types,

1. Abnormality would have resulted in death regardless of any other factor.
2. Major contributor to death but may have survived if born at term.
3. No contribution to death

A number of other data items were derived from the data collected. This included:

- Locality from electoral ward, which was derived from address.
- Age at death which was derived from date of death and date of birth.
- Social class which was derived from fathers occupation. Where this was unavailable mothers occupation was taken. Sometimes neither was available so this was categorised as not known.

Analysis

Once finalised the data set was analysed for various frequencies and cross tabulations using SPSS.

Data issues

Cause of death

For a number of cases the data recorded by ONS varied from that summarised in the case notes. Sometimes this varied in the order recorded (i.e. 1, 2 etc) and sometimes items were omitted. Some of this variation arose in determining the role of other factors e.g. congenital abnormalities, particularly when prematurity and / or low birth weight were also factors.

This led to the involvement of a consultant neonatologist but some of the cases would have required further study of the case notes, which was not considered appropriate, at this stage.

Registration

Five cases had to be excluded as few data items could be obtained. These cases had not been fully registered despite the length of time since death. A number, if not all, were assumed to be with the Coroner. Given the numbers of cases involved this could skew analysis. Of more concern is the impact on IMR in future years. The IMR for north Kirklees in 2002 was high, partly because of a 'catch up' by ONS in registered deaths, which is used as the numerator. We would strongly recommend that IMR is derived from date of death, not date of registration which can vary considerably.

Missing data items

To really establish a clear picture of what is happening, several data items are key. They should be mandatory items and steps taken to record them accurately. Of particular concern is the lack of recording of ethnicity in the various data sets. Ethnicity is clearly a factor, but any analysis is plagued by vagaries in recording details. To obtain South Asian cases Nam Pechan [Note 1] can be applied but for an analysis of, for example, factors affecting Afro-Caribbean populations, identifying them is very difficult.

Consistent recording of gestation would be helpful together with birth weight, as the two are inter-related.

Locally a number of items should be recorded antenatally, often at first booking. Although the timing of this varies, items should still be recorded. This analysis has shown this recording to be variable and often not available. The following table summarises particular items where case notes were missing and where data was not recorded.

The variation in case notes missing arises because a few items were deduced from other sources, particularly health visitor records, even though the maternal notes were missing, for example. Some of the missing case notes arose because these were in other hospitals and no attempt was made to obtain them.

The lack of data recording needs to be addressed locally, particularly for items required as part of DH monitoring, such as smoking status.

Of particular concern was the variable recording of screening data, both in terms of offering and uptake. It is unclear how national screening programmes can be monitored without more accurate recording of offer and uptake.

Table 7 – Summary of case notes unavailable and no data recorded

| | Case notes unavailable | No data recorded |
|--|------------------------|------------------|
| Understanding English | 23 | 41 |
| Consanguinity | 25 | 58 |
| Family history of congenital abnormality | 26 | 22 |
| Gestational age at booking | 26 | 12 |
| Role of maternal diabetes | 26 | 11 |
| Alcohol consumption | 26 | 14 |
| Previous pregnancies /parity | 17 | 2 |
| Smoking status | 25 | 6 |
| Mode of delivery | 13 | 4 |

[Note 1] Nam Pechan is a computer program which enables names from the Family Health Services list to be checked against a table of South Asian names. By then cross-matching with regional and language origin an estimate of the number of people of South Asian origin can be derived.

Appendix 3

Serious Untoward Incidents

MYHT has a robust incident reporting and risk management system. Incidents are reported on an incident reporting form, and logged on an IT system to allow analysis of incidents. Every incident is given a grading according to its severity, and is investigated.

If there is a death of any kind, the notes are reviewed by the midwifery and medical team as soon as possible after the event by the relevant professional groups i.e. Consultant Obstetrician, midwife, neonatologist. If the death is expected i.e. foetal abnormality, and/or the care is deemed to be appropriate, then the incident is closed. This information is recorded on the pink portion of the incident form, and the case is deemed to be closed. The relevant documentation is filed in risk management, and all information recorded on the Sentinel system (IT system).

If the case needs further investigation then the notes are reviewed by the Risk Management Leads (Head of Midwifery and Clinical Director). They then decide whether to undertake a full investigation (Root Cause Analysis (RCA)). A Root Cause Analysis is undertaken in cases where there are suspected failings in systems, or where there is a suspicion that there are lessons to be learnt and a new system or change in practice can be implemented.

A panel is selected on an individual basis to review the case, and undertake the Root Cause Analysis. A timeline is set and an analysis is undertaken at each step to identify the reasons why the incident occurred. The case is fully investigated, and a report is written with recommendations to prevent the chance of the same incident happening again.

This Root Cause Analysis is shared with the staff and the family involved, and the lessons learnt shared anonymously with other staff. The recommendations are monitored by the Women's Clinical Governance Group until they are completed.

If the case is deemed to be a Serious Untoward Incident (SUI) as defined by the SHA this is notified to the SHA, and LSA by the Medical Director for Clinical Governance and Head of Midwifery respectively. The RCA has to be completed in six weeks and submitted to the SHA.

Learning is paramount after all incidents and the systems in place allow non judgmental review of cases. This leads on to the sharing of lessons to reduce the chance of reoccurrence in the future.

Lois Fox

Clinical Governance Midwife
Mid Yorkshire Hospitals NHS Trust
June 2007

Appendix 4

Thanks

Access and Support

| | |
|-----------------------|--|
| Dr Keith Judkins | Caldicott Guardian, MYHT |
| Sharon Schofield | Head of Midwifery, MYHT |
| Dr Peter Mackay | Consultant Paediatrician, MYHT |
| Maxine Hey | Head of Delivery Suite, Dewsbury and District Hospital |
| Delivery Suite Staff | Dewsbury and District Hospital |
| Medical Records Staff | Dewsbury and District Hospital |
| Kim Nightingale | North Kirklees PCT |

Data Collection and Analysis

| | |
|-------------------|--|
| Catherine Smythe | Lead Nurse, Public Health |
| Karen Woodhead | Children's Modernisation Facilitator |
| Linda Webster | Child Health Services, North Kirklees PCT |
| Andrew Billington | Calderdale & Huddersfield Health Informatics Service |
| Paula Kelly | Calderdale & Huddersfield Health Informatics Service |
| Rosemary Earl | Project Officer (Public Health), North Kirklees PCT |
| Dr Bryan Gill | Consultant Neonatologist, Leeds Teaching Hospitals |
| Robert Scott | Portfolio Manager (Data Quality), North Kirklees PCT |

Other

| | |
|-----------------|--|
| Helen Brown | Bradford Informatics Service |
| Dr Liz Kernohan | Director of Public Health, Bradford City PCT |
| Lois Fox | Clinical Governance Midwife, MYHT |

Appendix 5

Improvements made by the Mid Yorkshire Hospitals NHS Trust

Data collection for the preparation of this report was undertaken in 2002. In April 2002, Dewsbury Hospital merged with Pinderfields and Pontefract Hospitals to form the Mid Yorkshire Hospitals NHS Trust. The Trust now has consultant led maternity services based on 2 sites (Dewsbury and Pontefract) and midwifery led units in Dewsbury, Wakefield and Pontefract. Since 2002 significant improvements have been made by the Mid Yorkshire Hospitals NHS Trust in standardising maternity services, and specifically addressing some of the concerns highlighted in this report.

Data quality

The recording of data has significantly improved by:

- The introduction of national hand held records which now include the recording of all the data fields required for this report apart from consanguineous marriage.
- The introduction of a new referral letter for pregnant women which forms the basis of a risk assessment to ensure women receive the correct care.
- The introduction of a computerised tracking system for all maternity notes using a scanning system so that location and retrieval of notes is improved.
- A new storage facility for maternity records at Dewsbury and District Hospital is in use.
- A new case note folder is also in use which supports good filing of records and ease of use.
- An annual multidisciplinary record keeping audit is performed to highlight areas for improvement.

Improvements in service delivery

The maternity service has made several improvements. These include:

- Delivering some maternity care through children's centres.
- Each midwife has received training in smoking cessation.
- Midwives are being trained in brief intervention around smoking cessation. This is mandatory for all midwives.
- A midwife is seconded to work with pregnant teenagers and main stream the work that she is developing.
- An infant feeding coordinator is in post to support the midwives and other staff to give good quality breast feeding support.
- The infant feeding coordinator is in the process of working with peer supporters so they will come and support breastfeeding mothers whilst they are in hospital.

Angela Watson, Mid Yorkshire Hospitals NHS Trust

